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Congress of the United States **House of Representatives**

Washington, **DC** 20515—1313

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COMMITTEE ON AGRICULTURE

SUBCOMMITTEE ON GENERAL FARM COMMODITIES AND RISK MANAGEMENT

SUBCOMMITTEE ON
HORTICULTURE, RESEARCH, BIOTECHNOLOGY,
AND FOREIGN AGRICULTURE

COMMITTEE ON TRANSPORTATION AND INFRASTRUCTURE

SUBCOMMITTEE ON AVIATION-VICE CHAIR

SUBCOMMITTEE ON HIGHWAYS AND TRANSIT

SUBCOMMITTEE ON WATER RESOURCES AND ENVIRONMENT

The Honorable Tom Cole Chairman Subcommittee on Labor, Health & Education House Committee on Appropriations 2358-B Rayburn House Office Building Washington, DC 20515

The Honorable Rosa DeLauro Ranking Member Subcommittee on Labor, Health & Education House Committee on Appropriations 1016 Longworth House Office Building Washington, DC 20515

Dear Chairman Cole and Ranking Member DeLauro:

In his State of the Union, President Obama shared a vision for a "Cancer Moonshot" that would make America "the country that cures cancer once and for all". I am writing to urge you to apply this same visionary approach to pediatric cancer research, and specifically pediatric brain cancer research, at the National Institutes of Health (NIH) and the National Cancer Institute (NCI).

Cancer is the leading disease-related cause of death among children in the United States, and brain cancers are the leading cause of cancer-related death in children across all ages. While increases in the 5-year survival rate for pediatric cancer have been observed since 1975, survival rates for children with certain types of brain cancer remain troubling – particularly because the incidence of childhood brain cancer has increased nearly 70 percent since the 1970s.

The combination of public and private investment in pediatric brain cancer has dramatically advanced scientific understanding of the pathways that are active in this disease. And scientists are realizing that not only are adult and childhood brain cancers very different, but that pediatric brain cancer is itself actually a broad spectrum of diseases that require a cross utilization of therapies. This newfound understanding of pediatric brain cancer is leading scientists in the field to the conclusion that pediatric brain cancer is uniquely well-positioned to benefit from a precision medicine approach.

Drug development for pediatric brain cancer has lagged as a result of the unique challenges facing researchers, including the lack of testing agents, the limited number of patients and available specimens for research, the lack of models for these cancers, and the challenges of delivering treatments through the blood-brain barrier. A specific effort to advance pediatric brain research through a precision medicine initiative that catalogues pediatric brain cancer could provide the foundation that is needed to spur drug development for pediatric brain cancer.

I am writing to request that the Committee expand the Precision Medicine Initiative to specifically include pediatric brain cancer, and to request a report from NIH on the specific steps that are being taken to address the unique research challenges facing children's brain cancer. NIH highlights enrollment in clinical trials at first diagnosis as a standard of care for children in the United States that has yielded success in identifying more effective treatments for childhood cancer. With limited access to drug development, these trials are often unavailable to pediatric brain cancer patients.

Escalating the focus on precision medicine and increasing pediatric brain cancer enrollment in the MATCH program could yield tremendous benefits. To achieve this goal, I urge the Committee to include the following report language:

National Cancer Institute – Report Language

Pediatric Brain Cancer: Great advances have been made in understanding children's brain cancers. Scientists are discovering that these cancers are actually a series of diseases with different genetic underpinnings that will require cross utilization of therapies. Given this emerging understanding of pediatric brain cancer biology, scientists have identified these diseases as especially well positioned to benefit from pediatric precision medicine approaches. The Committee directs the NCI to report on plans to utilize precision medicine to identify and test more effective, less toxic treatments, and to improve the targeting of treatments for children battling brain cancer. NCI should specifically report the following data by brain tumor type: clinical trials available for pediatric patients, including the number of patients enrolled in the precision medicine initiative; the number of therapies examined; and the status of access to tissue samples and genomic and clinical data available for research and discovery efforts.

In addition, I support the inclusion of the following report language to further address the need for advancements in research on pediatric cancer:

National Cancer Institute - Report Language

The Committee encourages NCI to continue its important investments in pediatric oncology research, including clinical studies for children with brain tumors, the important pediatric preclinical testing program evaluating new agents for treating pediatric malignancies and development of the novel pediatric Molecular Analysis for Therapy Choice (MATCH) study. The Committee requests an update on the progress of this important program, including the status of awarded grants and partnerships.

National Cancer Institute – Report Language

Recent NIH studies demonstrate that a new cancer immunotherapy method to specifically attack tumor cells that have mutations unique to a patient's cancer could be effective against a wide range of cancers. The Committee encourages the NCI to continue to further explore new interventions, such as immunotherapy, as a promising new treatment strategy for children with cancer.

National Cancer Institute - Report Language

The Committee has provided the NCI with funding for the Specimen Resource Locator, a searchable database of biospecimen collections. The Committee urges the NCI to require that its grant, contract or other award recipient administering the Locator report on pediatric cancer biospecimen collections.

National Cancer Institute – Report Language

Within the additional resources provided for cancer research, the Committee requests a report on how the NCI is focusing on the unique needs of children in its allocation of funding.

Research funding for all types of cancer is and remains highly important. As science drives the understanding of pediatric cancer, I urge you to require NIH and NCI to focus their efforts to take advantage of this better understanding to ensure that children battling cancer are given a chance to experience a future.

Thank you for your time and attention to this important matter.

Respectfully,

Rodney Davis

Member of Congress